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Patient drawings of their melanoma: A novel approach to understanding symptom perception and appraisal prior to healthcare consultation

Abstract

Objective: This pilot study investigated the use of patient drawings to explore patient experiences of symptoms of melanoma prior to healthcare use.

Design: Patients (n=63) with melanoma were interviewed within 10 weeks of diagnosis. Participants were asked to draw what their melanoma had looked like when they first noticed it, and to make additional drawings to depict changes as it developed.

Main outcome measure: The size and features of the drawings were compared between participants and with clinical data (thickness of the melanoma; histological diameter; clinical photographs).

Results: 84% of participants were able to produce at least one drawing. This facilitated discussion of their lesion and recall of events on the pathway to diagnosis. Common features of the drawings related to the view, presence of shading, inclusion of sections, and the shape and border of the lesion. There was potential for disparity between the details in awareness resources and the perceptions of patients. The drawings resembled the clinical photographs and the size of the drawings was positively associated with the histological diameter, but did not differ according to tumour thickness.

Conclusion: Asking patients to make drawings of their melanoma appears to be an acceptable, inclusive, feasible and insightful methodological tool.

Keywords: Drawings; Early diagnosis; Help-seeking; Melanoma; Cancer

Patient drawings of their melanoma: A novel approach to understanding' symptom perception and appraisal prior to healthcare consultation

Background

The incidence of advanced stage cancer at diagnosis is frequently attributed to delays in detection and presentation (Thomson & Forman, 2009; Abdel-Rahman, Stockton, Rachet, Hakulinen, & Coleman, 2009; Neal, Allgar, Ali, Leese, Heywood, Proctor & Evans, 2007). In order to develop ways of reducing undue delay, it is important to understand the processes of symptom perception (awareness, attention to and appraisal of bodily changes), and the timing and reasons underlying help-seeking behaviour. The Model of Pathways to Treatment (Scott, Walter, Webster, Sutton & Emery, 2013) is a framework that outlines the processes and events that can occur leading up to and beyond symptomatic presentation to healthcare professionals. This framework incorporates existing psychological theories such as the Common Sense Model of Illness Self-regulation (Leventhal, Meyer & Nerenz, 1980) and Social Cognitive Theory (Bandura, 1998) in order to explain the decision to seek medical help, and highlights the importance of patient symptom representations, their previous experiences, concurrent demands or goals and their beliefs about healthcare.

Ideally, research into time to presentation (defined as the appraisal and help-seeking interval i.e. from the first detection of a symptom to the first consultation with a healthcare professional (Scott et al., 2013)), would encompass prospective designs, studying symptom perception and help-seeking behaviour as it happens. However it is questionable as to whether such longitudinal, prospective studies can be conducted for diseases such as cancer: it would be unethical to observe a patient with probable or possible symptoms of cancer without recommending they

consult a HCP (Scott & Walter, 2010). Further, studying an initially asymptomatic sample and monitoring how and when they notice potential symptom of cancer is unlikely to be feasible. Most early diagnosis research is therefore retrospective, involving samples of patients who have recently sought help for potentially malignant symptoms or those whom have recently received a cancer diagnosis. Such use of retrospective data is problematic as it has the potential to result in error in recall, particularly for those patients who waited a considerable amount of time before seeking help. New methodological adjuncts are therefore being recommended to improve the robustness of early diagnosis research (Weller, Vedsted, Rubin et al., 2012). For instance, use of calendar landmarking instruments (Glasner, & van der Vaart, 2009), may aid recall. However, additional, innovative ways are needed to explore the patient perspective about what occurs prior to consultation with healthcare professionals and the influences on time to presentation.

It has been suggested that patient drawings might be able to offer insight into patient experiences and identify aspects of perceptions of illness that are not easily accessible by interviews or questionnaire (Kaptein, & Broadbent, 2007). Patient drawings may be able to ‘illustrate ideas in a more concrete and specific way than words’ (Broadbent, Ellis, Gamble & Petrie, 2006) and could help clinicians better understand the context of patients’ experiences (Mays, Strum, Rasche, Cox, Cox & Zimet, 2011). Drawings have not previously been used in early diagnosis research, but have been used to study patient experiences and perceptions of diagnosis and recovery of various health conditions. Size of drawings (e.g. height, surface area, or change in size between drawings) has been linked to clinical markers of worse disease severity, adaptation (e.g. return to work) and psychological outcomes (e.g. anxiety and depression; worry about recurrence) in patients with myocardial infarction (Broadbent, Ellis, Gamble & Petrie, 2006; Broadbent, Petrie, Ellis, Ying & Gamble, 2004), heart failure (Reynolds, Broadbent, Ellis,

Gamble & Petrie, 2007), cerebral palsy (Chong, Mackey, Stott & Broadbent, 2013), and Cushing's syndrome (Tiemensma, Daskalakis, van der Veen, et al., 2012). Other features of patient drawings (e.g. depictions of external force, intensity of pen strokes) have also been linked to clinical severity or adjustment to disease (Broadbent, Niederhoffer, Hague, Corter & Reynolds, 2009).

In relation to cancer, drawings have been used to gain insight into children's experiences and understanding of cancer [Ångström-Brännström & Norberg, 2014; Woodgate, West & Taylor, 2014) but have rarely been used with adults. Studies have focused on psychological phenomena (e.g. the meaning of hope (Hammer, Hall & Mogensen, 2013)), response to psychological intervention (Ho, Potash, Fu, Wong & Chang, 2010) or adjustment following treatment (e.g. body image following mastectomy, (Perdikis, Fakhre, Spped & Griggs, 2011)) but not for research into early diagnosis.

Drawings have the potential to offer useful insights into symptom perception and patient perspectives of the development of their cancer. This may particularly be the case with melanoma, where patients often notice a visible change in their skin, which can gradually develop over months or years. Understanding how patients notice, appraise and respond to these skin changes is vital, given the prognosis for thinner melanomas (e.g. a primary cutaneous melanoma $\leq 1\text{mm}$ at diagnosis) is far better (over 95% 5-year survival) than for thicker melanomas ($\geq 2\text{mm}$ at diagnosis, less than 55% 5-year survival)(Cancer Research UK, 2014). Given some suggestions that some patients dismiss skin changes as normal (Nyawata & Topping, 2006), or dismiss the potential severity of skin changes (Hajdarevic, Hörnsten, Sundbom, Brulin & Schmitt-Egenolf, 2010), it is unknown as to whether patients are able to recollect appearance of lesions and the changes that occurred prior to seeking help, or whether

these representations bear any resemblance to the appearance of the lesion (e.g. as seen in clinical photographs).

The current research is an exploratory pilot study to investigate the potential for incorporating patient drawings into research investigating early diagnosis of melanoma. The study aimed to discover (a) whether patients are willing and able to make a drawing of how they perceived the appearance of their melanoma when they first noticed a skin change, and any subsequent changes; (b) If patients can produce drawings, what features do participants depict in their drawings?; (c) Does the size of drawings differ between patients with thinner and thicker melanoma or relate to time to presentation?; and finally (d) Do patient drawings of their melanoma relate to the actual size or appearance of the melanoma at diagnosis?

Methods

Sample

This study was a part of a semi-structured, face to face in-depth interview study, the details of which are described elsewhere (Walter, Birt, Cavers et al., 2014). Briefly, participants were identified and recruited by the melanoma/skin cancer nurse specialists at two regional hospitals (Cambridge University Hospitals NHS Foundation Trust; Edinburgh Royal Infirmary, NHS Lothian). Participants were required to be over 18 years of age and have been recently diagnosed with a primary malignant cutaneous melanoma. As thicker melanomas (>2mm Breslow thickness, less favourable prognosis) are diagnosed at about 25% of the rate of thinner melanomas, we recruited all those with thicker melanomas who wanted to take part. At the same time we purposively sampled people with thinner melanomas (<1mm Breslow thickness, excellent prognosis) by age group (<50, 51-70, >70), gender (male, female) and location (Cambridge, Edinburgh) to ensure that we had a broad range of perspectives and experiences. To do this we drew up a grid of the sampling characteristics to select at least one and no more than three participants from each composite category.

Procedure

Interviews were completed within 10 weeks of diagnosis. The interview schedule focused on the cognitive, emotional and behavioural processes that occurred within the appraisal interval (the time from detection of a bodily change to perceiving a reason to discuss symptoms with a healthcare professional) and the help-seeking interval (the time from perceiving a reason to discuss symptoms with a healthcare professional to the first consultation with a healthcare professional about their symptoms) (Scott, Walter, Webster, Sutton & Emery, 2013). Time to

presentation was determined through the interviews with participants. This included the use of a calendar landmarking instrument to aid recall of the timing of events.

During the in-depth interviews, researchers asked participants to draw a picture of what they remembered their melanoma to look like when they first noticed it. They were also invited to make additional drawings of their melanoma as it developed, up until the time of diagnosis. In line with previous drawing research (Broadbent, Ellis, Gamle & Petrie, 2006), participants were reassured that we were not interested in their drawing ability; a simple sketch was fine. Participants were provided with a standard pencil and an A4 sheet of paper with 4 blank boxes in which to draw their melanoma. Each box measured 60mm X 80mm. Above the boxes there were images of a fifty pence (diameter = 27mm), two pence (diameter = 26mm), ten pence (diameter = 25mm), and five pence piece (diameter = 18mm), in order to provide scale for the drawings. Participants could annotate drawings themselves or the researcher annotated the drawings on behalf of the participant.

Medical records were used to obtain details of participants' age, gender, tumour classification (e.g. nodular melanoma (NM), superficial spreading melanoma (SSM), lentigo maligna melanoma (LMM), tumour thickness (staged as ≤ 1 mm (T1, 'thinner') or ≥ 2 mm (T3 and T4, 'thicker'), and the diameter of the melanoma as stated in the histology report. Clinical photographs of the melanoma at the time of diagnosis were requested from the medical records at the treating hospital. However, many (n=46) were unavailable or unsuitable (e.g. because clinical photographs had not been taken; photos were taken by the referring rather than treating hospital thus were not taken at the time of diagnosis; photos did not include a scale of measurement; or there was a lack of participant permission to access the photos).

Ethics approval was obtained from the Cambridgeshire 4 Research Ethics Committee (11/EE/0076) and locally from the Lothian Research Ethics Committee.

Qualitative Analysis

Each drawing was qualitatively assessed by identifying the prominent aspects of the drawings (in line with previous assessments of patient drawings (Boradent, Niederhoffer, Hague, Corter & Reynolds, 2009)). These initial assessments were used to develop a coding framework of the features depicted in the drawings, which was then applied independently to each drawing by two researchers (SS and NS). Comparison of the coding indicated relatively few discrepancies. The few areas of disagreement included: definitions/descriptions of different types of borders, inclusion/exclusion of analysis of annotation, difference between shading and adding 'texture' to drawings. This led to discussions to reach consensus and produce the final coding framework and its application. Features depicted in drawings from participants diagnosed with thinner melanomas were compared to those with thicker melanomas.

The coding framework used for the drawings was subsequently applied to the clinical photographs. Within-participant comparisons were used to compare the features depicted in the drawings to those within the clinical photographs.

Quantitative Analysis

Each patient drawing was scanned to produce an electronic copy. The size of each 'aerial' drawing was calculated using ImageJ software (version 1.47v, (Rasband. n.d.)) as reported in

previous studies of patient drawings (Broadbent, Petrie, Ellis, Ying & Gamble, 2004). The scanned drawings were converted to grayscale and the measurement scale was set and applied to all the images to ensure they were measured with the same scale ratio. Each drawing was outlined using the 'free-hand' function to allow for flexibility to draw around irregular shapes. Once the outlines of each drawing were marked, the area was calculated (surface area in mm²). For those participants who drew more than one drawing, change in size (change in surface area in mm²) was calculated as the difference in area between 'first' and 'last' drawing.

Inferential statistics were used (chi square, independent t-test, pearson correlation, one-way ANOVA as appropriate, using SPSS, version 21) to determine if the number of drawings, the size of the drawings, and the overall change in size over time differed with age, gender, tumour thickness, time to presentation or melanoma classification. In the three cases where someone other than the participant (e.g. participant's daughter) had made the drawing, the gender of the participant was used for analyses of gender. It is acknowledged that people other than the patient may see the lesion in a different way to patients, however in this case the participants oversaw the drawings made by their relatives on their behalf. Spearman's rank correlations were used to determine the relationship between the size of the drawings and the diameter of the melanoma as stated in the histology report. For all analysis $p < 0.05$ was used as the level of significance.

Results

Sample characteristics

Of 241 adult patients who were approached to take part in the study, 121 were willing to participate and, as a result of the purposeful sampling, 63 of these were interviewed. 32 participants (51%) were female. The mean age of the sample was 63.7 years (range 29-93 years). Thirty-three participants (52%) had thinner melanoma and 30 (48%) had thicker melanomas. The majority of participants (n=35, 56%) were diagnosed with SSM, 10 participants (16%) had NM, 9 participants (14%) had LMM and the remaining 9 (14%) had other (e.g. acral, malignant blue naevus) or unclassified melanomas. Four participants had their melanomas diagnosed opportunistically by a HCP. For the remainder, the time to presentation was between 1 week and 303 weeks.

Number of drawings

53 (84%) of the 63 participants provided a drawing of their melanoma; three were drawn by the participant's wife or daughter. Drawing encouraged people to think more deeply about the appearance of the skin lesion and during the drawing they began to describe their lesion in more detail and to articulate the changes that happened over time. When participants were struggling to find the language to describe the lesion, the opportunity to draw was welcomed. Drawing also served another important function in these sensitive interviews, providing an opportunity for diversion away from intensive face- to-face questioning.

Participants did not provide a drawing for the following reasons: mole not seen (n=4); no desire to draw (n=2); not asked as appeared too anxious or distressed (n=2); unable to draw due to illness (n=1); drawing of wrong skin lesion (n=1). There was no difference in terms of age ($t=0.86$, $df=61$, $p=0.392$), gender ($\chi^2=0.403$, $df=1$, $p=0.525$), melanoma thickness ($\chi^2=0.28$, $df=1$, $p=0.599$), time to presentation ($t=-1.47$, $df=57$, $p=0.148$) or melanoma classification (NM vs SSM vs LMM/other) ($F(2,62)=0.49$, $p=0.616$) between those who did and did not draw their melanoma.

Each participant drew 1 - 7 drawings (mean=2.6 drawings (SD=1.5); median=2 drawings). Thirty-seven participants (59%) produced more than one drawing, resulting in 137 drawings between the 53 participants. There was no relationship between the number of drawings and participants' age ($r=-0.07$, $p=0.617$), tumour thickness ($t=-1.46$, $df=51$, $p=0.152$), time to presentation ($r=0.07$, $p=0.617$) or melanoma classification ($F(2,52)=1.98$, $p=0.381$). However, men drew significantly more drawings (mean=3.0) than women (mean=2.15) ($t=2.14$, $df=51$, $p<0.05$).

Features of the drawings

The qualitative assessment of the drawings indicated that they had various features in terms of their 'view', 'presence of shading', inclusion of 'sections', their shape and the type of 'border'. These are each discussed in turn.

'View'

Drawing an ‘aerial view’ of the melanoma was most common. Some participants with thicker melanoma also drew a ‘side view’ of the melanoma (see **Figure 1**).

Shading

Shading or ‘colouring in’ of the drawings was a fairly common feature (n=42), but many drawings (n=95) were left clear. Participants often annotated the drawing about the colour (e.g. “*pinkish-red*”, “*dark brown*”, “*became darker*”) rather than depicted it in their drawing. Some participants with thicker melanomas switched between shading one drawing and leaving other drawings clear, whereas the presence of shading in drawings from those with thinner melanomas tended to stay the same across drawings (see **Figure 2**).

‘Sections’

Some drawings featured different sections of the melanoma, and this was often a feature of drawings of how the melanoma changed over time, with initial drawings having one section and later drawings portraying two or more sections. This appeared similar for those with thinner and thicker melanomas (see **Figure 3**).

Shape

Participants’ melanomas were mostly drawn as an oval or circular shape, or less commonly, an asymmetrical patch. Three drawings included a square or rectangular shape. There were relatively few instances where the shape of the melanoma changed between drawings. In the few (n=7) that did change, there seemed to be no pattern. Some (n=4) started as oval or rectangular and become asymmetrical whereas others were initially asymmetrical (n=2) or rectangular (n=1) which become oval.

Borders

Drawings varied in how the edge of the melanoma was depicted. Most commonly, the border was smooth and continuous (e.g. ID:522, see **Figure 1**; ID:583, see **Figure 2**). Other drawings had rough borders, where the edge was textured but without sharp edges or spikes (e.g. ID:620, see **Figure 2**; ID:173, see **Figure 3**). Least common was a jagged border which consisted of pronounced, angular edges (e.g. ID: 148, see **Figure 2**; ID:533, see **Figure 3**). The way in which borders were drawn appeared similar between those with thicker and thinner melanomas. However, where change over time was drawn there was some indication that the drawings of those with thinner melanomas generally started with smooth borders that became rough or jagged, whereas some of those with thicker melanomas appeared to start with rough borders which then became smooth.

Size of the drawings

Four participants only drew a side view of the melanoma. Further, 9 early participants did not draw on the proforma, but instead drew on plain A4 paper (as the proforma was not available for the initial interviews). These 13 participants were not included in the analysis of the size of the drawings. As such the analyses concerning initial size of the drawings is based on the remaining 40 participants with aerial drawings. 29 of these 40 participants drew more than one drawing.

The size of participant's initial drawing ranged from 1.8mm^2 to 408.9mm^2 (mean= 91.3mm^2 (SD= 104.95mm^2); median= 51.0mm^2). Spearman's rank correlation coefficients indicated that the size of participant's initial drawing was positively correlated with the diameter of the melanoma as stated in the histology report ($n=35$; $\rho=0.47$, $p<0.01$).

The size of the participant's final drawing was also positively correlated with the histology diameter ($n=35$: $\rho = 0.57$, $p<0.0001$). The change in size of the drawing between the 'first' and the 'last' drawing ranged from -96.10mm^2 (note some ($n=4$) reduced in size e.g. ID:620, see **Figure 2**) to 295.84mm^2 (mean= 54.8mm^2 ($SD=84.44\text{mm}^2$); median= 29.4mm^2).

There was no relationship between the size of the initial drawing or the change in size of the drawing and participants' age (initial drawing: $r=0.21$, $p=0.193$; change in size: $r=0.25$, $p=0.184$), participant's gender (initial drawing: $t=0.09$, $df=38$, $p=0.930$; change in size: $t=0.78$, $df=27$, $p=0.443$), tumour thickness (initial drawing: $t=0.13$, $df=38$, $p=0.897$; change in size: $t=0.01$, $df=27$, $p=0.996$), time to presentation (initial drawing: $r=-0.002$, $p=0.99$; change in size: $r=-0.10$, $p=0.597$), or melanoma classification (initial drawing: $F(2, 39)=1.16$, $p=0.325$; change in size: $F(2,28)=1.01$, $p=0.378$).

Comparison between drawings and clinical photographs

Clinical photographs of the melanoma at the time of diagnosis were available for 17 participants who produced a drawing. Overall, the features of the drawings and the clinical photographs overlapped, some strikingly so (see **Figure 4(a)**). Only for two participants were the drawings and photographs considered to differ in some way. One participant's drawing (ID:171) was clearly defined as a rectangle and circle shape whereas the lesion in the photograph appeared to be an asymmetrical patch. Another participant's (ID:565) drawing was a circular shape with uniform colour whereas the photograph appeared to be an oval/asymmetrical shape encompassing different shades within it (see **Figure 4(b)**).

Conclusions

This is the first study to investigate patient drawings of their melanoma and is the first instance of investigating patient drawings in the context of early diagnosis of cancer. The findings are promising. On the whole, patients were able and willing to make a drawing of how they perceived the appearance of their melanoma when they first noticed a skin change and the drawings enhanced the data gathered in the interviews. A majority (59%) also drew additional drawings depicting how their melanoma changed over time. The characteristics of those who did not produce drawings did not differ from those who did. There were also few differences in number of drawings in relation to clinical or demographic details. This indicates that asking patients to make drawings could be an acceptable, inclusive and feasible methodological tool for early diagnosis research. It is noted that men did draw more drawings than women. Given the paucity of research into patient drawings, the robustness and reasons for this are unknown, but it is an interesting avenue to follow up in future research.

The ease with which patients depicted their melanoma and the level of detail in many of the drawings indicates that patients pay attention to their skin changes rather than deny or dismiss them (albeit the significance of the lesion or need for medical care may be dismissed). It has been suggested that symptoms may have to be severe and/or impact daily activities (as opposed to gradually developing symptoms that do not disrupt functioning) in order for patients to recall of the precise time of onset of symptoms (Sheppard, Kumar, Buckley, Shaw & Raza, 2008). Yet for the gradually changing skin lesions, participants were still able to depict the appearance of their first and subsequent skin changes. This finding presents opportunities for the refinement of community-level interventions and public awareness campaigns which focus on appraisal of skin

changes to prompt understanding of the meaning and significance of the changing lesion and the need to seek medical care.

Even more encouraging is that patient drawings of their melanoma did appear to relate to the actual size and appearance of the melanoma at diagnosis. This was the case even though participants were asked to draw a simple sketch rather than a very detailed and accurate drawing; it is plausible that an even closer match could be found if drawing instructions were altered. There was a positive relationship between the initial drawing size and the histology-recorded diameter of the melanoma. This relationship became stronger when the ‘final’ drawing (i.e. the drawing closest in time to the diagnosis) was compared to the histology diameter. Furthermore, on the whole the features depicted in drawings were strikingly similar to those seen in the clinical photographs. Previous studies have not found such close correspondence. For instance, Hoogerwerf, Ninaber, Willems, & Kaptein (2012) studied the drawings of a small sample ($n=12$) of patients with lung cancer and assessed the ‘correctness’ of the size and shape of the drawings compared to radiographs and found wide variation between patients. Some drew a ‘perfect copy’ whereas others had very little resemblance to the radiograph. The ‘accuracy’ of patient drawings in the current study may be due to the visible nature of melanoma, as opposed to asking patients to depict their internal organs.

The features of participants’ drawings offer a fascinating insight into how the patients perceived their skin changes prior to seeking medical attention. Some of the features depicted in patient drawings match those noted to be common symptoms of melanoma in the widely used Glasgow 7point checklist (Makie & Doherty, 1991) or the ABCDE mnemonic (Abbasi, Shaw, Rigel, Friedman, McCarthy, Osman, Kopf & Polsky, 2004). For example, participants depicted changes in their skin lesions by making more than one aerial view drawing, and for most, the subsequent

drawings were larger than the initial drawing, supporting the ‘change in size’ point of the Glasgow 7-point checklist. Participants also depicted changes in colour, by shading or annotating drawings, reflecting another element of the Glasgow 7-point checklist. In future studies, insight into colour change could be enhanced by providing a range of coloured pencils rather than just a standard pencil. However, some features of patient drawings appeared to differ from the checklists. For instance, the Glasgow 7-point checklist notes that a sign of melanoma is a ‘change in shape’ of a skin lesion. In the current study, the overall shape of drawings rarely changed, yet instead some patients depicted an increasing number of sections to their melanoma. Further, the ABCDE mnemonic notes ‘Asymmetry’ and ‘Border irregularity’ as common features of melanoma. Although these were present in some drawings, the majority of participants depicted symmetrically shaped lesions with smooth borders. This may indicate a potential for disparity between the details in awareness resources and the perceptions of patients. This is further supported by language used by participants in explanations of their symptoms (Walter, Birt, Cavers et al. 2014).

This pilot study found no significant associations between the size of patient drawings and time to presentation. Thus, time to presentation seems to be dependent on features other than size or degree of change in size. This supports data indicating that it may be patient’s interpretations of the meaning of symptoms rather than the nature of the symptoms themselves that underpin the decision to seek help (Nyawata & Topping, 2006). Given that previous research has shown aspects of drawings can be related to thoughts and emotions about illness (e.g. Daleboudt, Broadbent, Berger & Kaptein, 2011), future research could investigate associations between features of melanoma drawings and illness/symptom perceptions, or cognitive, emotional and behavioural processes.

Size of patient drawings was not related to melanoma thickness at diagnosis. However, in the current study there did appear to be some differences in the features depicted by participants with thicker melanomas. Some participants with thicker melanomas drew a 'side view' of their melanoma, depicting elevation from the skin; they also varied the shading within their drawings and depicted lesions with rough borders that became smooth. These features were not depicted in the drawings of participants with thinner melanoma. Although size of patient drawings has been reported to be associated with clinical outcomes elsewhere, not all previous drawing research has found such links. For instance, Luthy, Cedraschi, Pasquina, Uldry, Junod-Perron & Jassens (2013) reported that the size and features of drawings of patients with COPD were not related to measures of function/quality of life, anxiety, depression or clinical indicators of disease severity.

Being a pilot study, the current research has a number of limitations which should be considered and addressed in future research. Firstly, this study was embedded in a larger research project that used purposeful sampling for those with thinner melanomas. Although this group was matched for gender, age, geographic location and season, data based on a consecutive sample would be more generalisable. Secondly, unlike in the current study, it is noted that in previous drawing research participants have not been given a reference scale on the paper they drew on. Provision of the scale may have impacted the size of the drawings. Thirdly, there is a question concerning the reliability of patient drawings given the retrospective nature of this research. Patients were asked to complete the drawings within 10 weeks of diagnosis, but the time at which they first noticed a change in their skin could have been many more weeks, if not months before this. Fourthly, the study had a relatively low sample size, especially for the analysis of change drawings and the comparison to clinical photographs. Future sample size calculations should allow for up to 40% of participants to only make one drawing and that clinical

photographs may not necessarily be a part of routine care or available for research. Finally, the features of drawings could be compared quantitatively and there are a number of additional quantitative analyses that would be interesting to include should sample size allow. For instance, proportion in change in size rather than actual change in size of drawings, different features of drawings in relation to time to presentation and tumour thickness; and the change in elevation depicted in ‘side view’ drawings, including consideration to the change that prompted a perceived need to consult a healthcare professional.

This study has introduced the methodology of patient drawings to research into early diagnosis and indicates that this may be an insightful methodological tool. Patient drawings add a deeper understanding of patient perception of their lesion. It is acknowledged that drawings alone may be unable to depict sensations (e.g. in the case of melanoma, oozing, crusting, itching, bleeding), unless annotations and concurrent discussions are incorporated into the analysis. Therefore drawings should be seen as an adjunct rather than alternative to interview or questionnaire data that facilitate discussion of symptom perception and appraisal, in order to gain a richer understanding. Whether or not drawings can be applied to early diagnosis research for other cancer types remains to be investigated.

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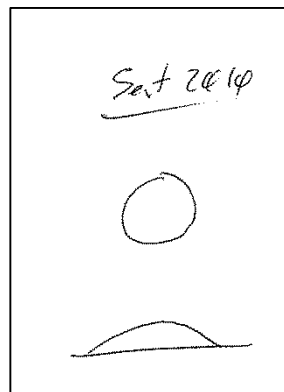
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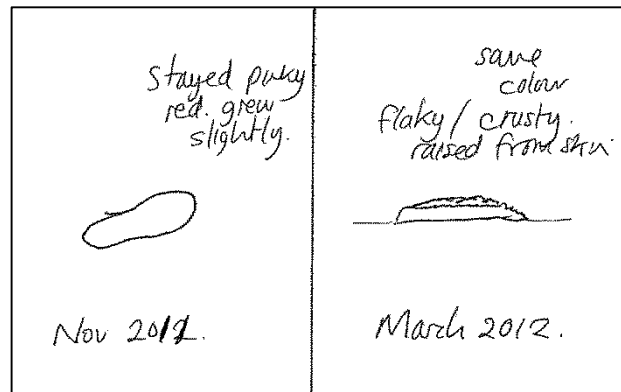
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Figure 1: Examples of aerial and side view drawings

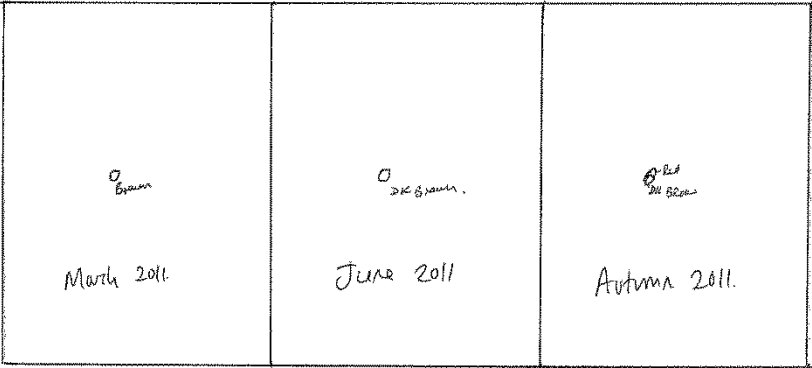


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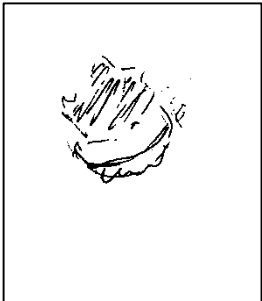


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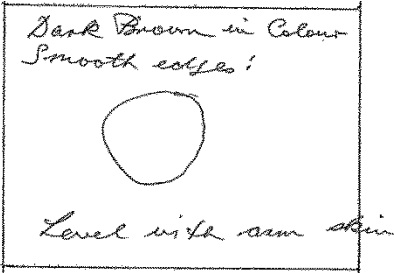
Figure 2: Examples of clear and shaded drawings



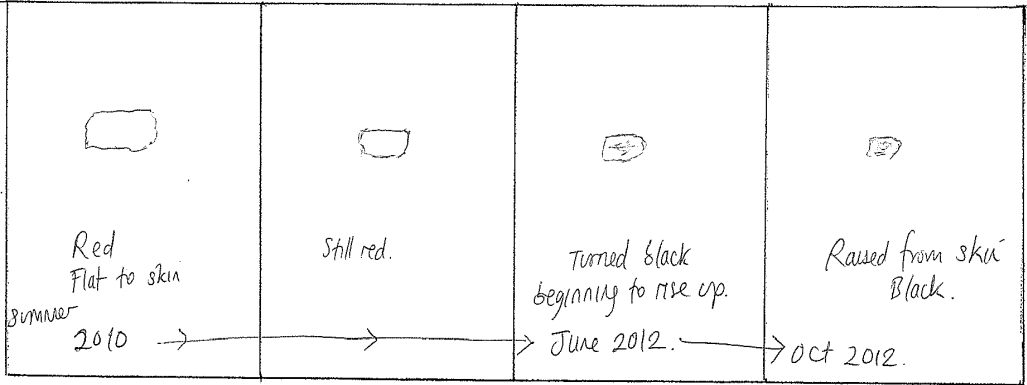
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ID148 (Thinner)



ID583 (Thinner)



ID620 (Thicker)

Figure 3: Examples of ‘sections’ within drawings

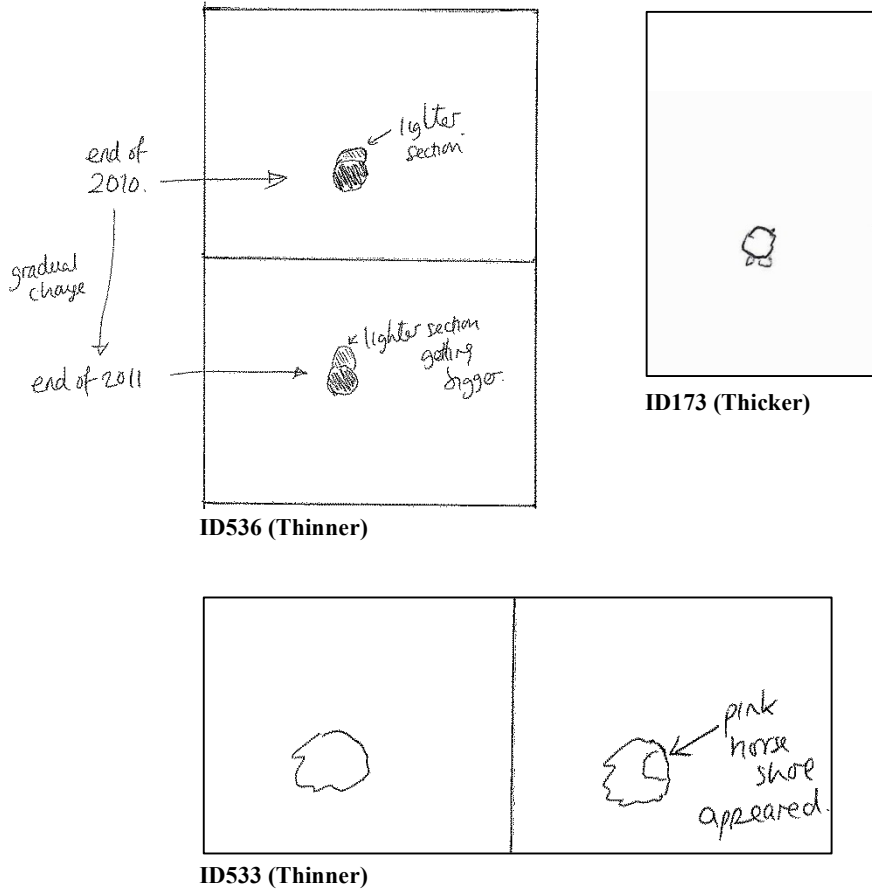
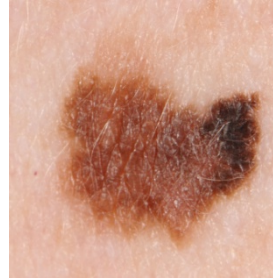
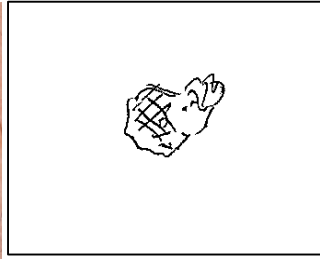


Figure 4: Comparison of drawings and clinical photographs

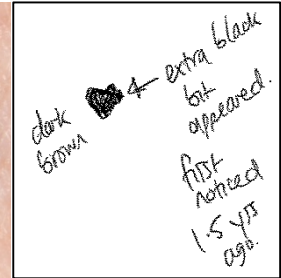
(a) Good likeness between drawing and photographs



ID529 (Thinner)



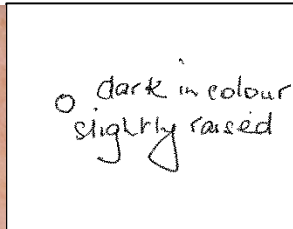
ID559 (Thinner)



(b) Discrepancies between drawing and photographs



ID565 (Thicker)



ID117(Thinner)

